

National Center for Complementary and Alternative Medicine

Strategic Planning:

Information and Communication about CAM Research and Decisionmaking about CAM Use

Summary of Public Comments

Since its creation as an independent Center in 1998, the National Center for Complementary and Alternative Medicine (NCCAM) has twice developed strategic plans (2000-2004; 2005-2009) to help guide the implementation of its legislative mandate, including its communications efforts. This third strategic planning process has the advantage of a decade of experience on which to base new approaches and strategies. This provides an opportunity to ensure optimal alignment of NCCAM's communications strategies with need and assess what we know about how the public makes decisions about CAM use, and how health care providers incorporate CAM modalities into their practices. To aid the strategic planning process, NCCAM posted a document on its Web site in September 2009 and invited public comments regarding the general topic of consumer practice and provider knowledge about CAM research, and NCCAM's communications strategies.

This paper provides a summary report of the public comments that were received. It does not necessarily represent the views or conclusions of NCCAM, which are still in the process of being developed, about either the white paper or the comments received.

Issues of Interest

The public was asked to provide feedback on three specific issues regarding NCCAM's communication efforts:

Issue 1: The major unmet needs of consumers and the general public in accessing, interpreting, and making use of research evidence about CAM.

Issue 2: The major unmet needs of healthcare providers in accessing, interpreting, and making use of research evidence about CAM.

Issue 3: Research needed to better understand how both healthcare providers and the general public make decisions about CAM practice and use.

Respondent Demographics

To address these issues of interest, 100 respondents provided input. Of the total respondents, 94 provided optional demographic information. The majority of these respondents self-identified as CAM patients (46%) and/or practitioners (41%). Other populations that were represented included other

health care practitioners (12%), researchers (10%), students (4%), and “other” (14%). Nineteen respondents (20%) identified themselves with more than one category.

Methods

NCCAM posted the document on-line for six weeks and solicited comments from the general public via Federal Register, NCCAM Update, the NCCAM website (and RSS feed), and Twitter, as well as targeted emails to several hundred stakeholders (e.g., funded investigators, NCCAM Update subscribers, third party organizations). NCCAM staff reviewed all responses that were provided. Because respondents did not generally structure their feedback strictly according to the three issues, for this report comments were sorted into topics broadly relevant to the Information and Communication of CAM research. In the following compilation, closely related comments have been pooled together and are summarized as themes.

Unmet Needs of the Public

The first issue that was addressed by public comment was that of unmet needs of consumers and the general public in accessing, interpreting, and making use of research evidence about CAM.

- The public is relatively uninformed about basic research, so a national strategy to promote scientific literacy would help but may be beyond NCCAM’s scope. This would help the public better discern information based on controlled scientific studies from unfounded claims not endorsed by FDA.
- Consumers faced with medical conditions want fair and balanced information about all of their health care choices. Consumers want to be able to compare the potential benefits, risks, costs, availability, side effects, duration, resulting quality of life, and personal commitment that accompany each choice. Thus, it is essential that NCCAM communicate the latest scientific results in an applicable way.
- Consumers and the public are not the same audience, and NCCAM should be careful in targeting messages based on which audience it hopes to reach.
- When designing messages, care must be taken to present research results in terms that consumers can identify with and understand. Otherwise they may be likely to believe anecdotal evidence from the Internet that may or may not be true. A few respondents suggested that NCCAM develop public awareness brochures or fact sheets on various CAM therapies.
- Consumers get much of their information about CAM from popular media and the Internet. The majority of this information is biased in one direction or the other. NCCAM must continue to be active in providing press releases to the media about research results, and should provide the names of unbiased experts at NCCAM and elsewhere.

Unmet Needs of Health Care Providers

The second issue that was addressed by public comment was the major unmet needs of health care providers in accessing, interpreting, and making use of research evidence about CAM.

- Since many members of the public rely on their health care providers for any information pertaining to their health, it is important for providers to understand CAM uses and integrate CAM into their practices.
- As more providers are starting to incorporate some CAM modalities into their practice, there is a need to more effectively disseminate information that will enhance clinicians' knowledge, attitudes, and ability to communicate with patients about CAM.
- NCCAM could enhance its communications with conventional health professionals by partnering with professional organizations.
- Health care professionals should learn more about CAM practices during medical school, so that they can use an integrative approach to meeting patients' needs. One respondent suggested continuing education on CAM for physicians and providers, to ensure the latest research is considered.
- Since providers often are limited by time and access to journals, NCCAM should provide a centralized, authoritative, and systematic synthesis of research studies for free on-line. NCCAM should also provide reviews and meta-analyses of major CAM topics: acupuncture, chiropractic, and herbal medicines.
- NCCAM should develop a communication system that translates research into different levels or grades of evidence that support various levels of confidence for practitioner recommendations (based on safety and efficacy).

How People Make Decisions

The third issue addressed by public comment was what research is needed to better understand how both health care providers and the general public make decisions about CAM practice and use.

- Several respondents suggested using survey tools to study this issue. NCCAM should collaborate with professional organizations, since these organizations routinely survey their members on various opinions and practices. NHIS and other national surveys can continue to lend insight into research and communication needs.
- Some respondents felt that NCCAM should not make this research a high priority. The research does not need to be done because NCCAM's role is to simply guide the public in the right direction.

- According to some, the answers are obvious: the public makes decisions based on what has or has not worked for them and their acquaintances, on what they read, on what they can afford, and on who listens to them.
- Research studies could take a more holistic assessment of the economics of CAM, as most decisions are based on money, by analyzing the cost-benefit rather than cost-effectiveness of CAM.
- It would be helpful to identify and gain a better understanding of unsubstantiated biases held by practitioners on both sides of the issue, and how these biases influence decision-making about the use or avoidance of a particular modality. Understanding these biases is the first step in eliminating them, so that the public can make informed choices.

Other Comments

- Many respondents suggested particular diseases, conditions, or CAM modalities as specific topics meriting research. A large number of homeopathic practitioners suggested that NCCAM place more emphasis on studying homeopathy by consulting with leaders in the field to design trials and identify areas of scientific promise.
- NCCAM should communicate the existence of different levels of evidence that support interventions.
- NCCAM should provide meta-analyses of topics that are written by independent authors.